

ELSI: Origins and early history

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Proposal to map the human genome: social and ethical concerns

- Proposals to map the human genome emerge in the mid-1980s
- Social and ethical issues highlighted in OTA and NAS reports evaluating the advisability of proceeding
- Do not make any suggestions about how to address
- Press conference. October 1988.
 - James Watson declares that social and ethical issues will be addressed through a program housed in NIH and funded by a 3 to 5 % set aside from the Human Genome Project budget

ELSI: A Research Mandate

- ELSI created as an NIH research program based on investigator-initiated research awards
- Philosophers are chosen as first two directors
- First mission statement lists nine research areas including:
 - individual psychological responses to knowledge of genetic variation
 - uses and misuses of genetics in the past
 - conceptual and philosophical implications of the Human Genome

ELSI: A Policy Mandate

- Congress expresses ongoing concern over how HGP would handle potential social and ethical issues
- Watson declares: ELSI will create policies
- No guidelines
- Unrecognized gap between expertise required for basic philosophical, ethical, legal and sociological research and policy making

Ethics as misunderstanding, mistakes, & misconduct

- Watson: we must “ensure that society learns to use the information only in beneficial ways”
- Problems are external to the science:
 - public misunderstands claims about the relationship between disease and genetics; health insurers misconstrue the significance of carrier status; scientists exaggerate significance of findings
- Solutions are technical, practical, and targeted

Ethics as the relationship between science and the common good

- Normative inquiry
 - Not only RCR questions: Is it true? Is it fair? But also: is it wise?
 - What ought to be done?
- Sociological inquiry:
 - How are topics are chosen and research designed?
 - For whom and in what ways will the results be useful?
 - Cui bono? Does the research perpetuate or ameliorate health disparities?

Bridging the gaps: Creating new communities

- NIH-DOE Working Group on Ethical, Legal, and Social Implications of Human Genome
- ELSI research consortia